



Missouri Organ Donor Registry

Web-Based Registry Team Receives Governor's Award

The development and implementation team for the Web-based Organ Donor Registry was selected for the prestigious **Governor's Award for Quality and Productivity for 2003**. The team was one of nine selected from 81 nominations from various state agencies and offices. A statewide recognition ceremony will be held in honor of the award-winning teams. The 24 members of the registry team are listed below.

Registry Team Members		
Faye Zumwalt	Cheryl Tyner	Jim Findlay
Marilyn Dickneite	Charlie Verhoff	Rich Wyble
Paula Peters	Janice Brand	John Claas
Tom Snodgrass	Jeff Elliott	Tom Meeks
Phil Reed	Mike Schweiss	Devon Christensen
Cyndi Rackers	Shannon Bryant	Marianne Ronan
Mark Bailey	Betty Schobey	Lori Darr
Mark Mantle	Tom Sholes	Elena Giesing

Wife Tells of the True Impact of the Registry

Vanetta Wick describes her personal experience with Missouri's Organ Donor Registry and the death of her husband, Nathan. Ms. Wick explains, *"I was somewhat sure that he would want to be an organ donor though I could not recall that we had ever really discussed it. I checked the back of his driver's license; it was not signed. At this devastating time of unspeakable despair I found myself dealing with a decision only Nathan should make. I knew that whatever I decided, doubt would haunt me forever.... It was then that an organ donor coordinator told me that Nathan had been asked about organ donation when he renewed his driver's license just five months earlier. She had a copy of the recorded response with her to show me. Nathan had, indeed, wanted to be an organ donor.... I cannot tell you what a relief and a blessing it was to know for certain what he wanted and be able to carry out his wishes. I am so grateful that I will not have to live the rest of my life wondering if I did the right thing for this wonderful man I adored. I am so thankful there was a mechanism in place to tell me his wishes when he was no longer able to tell me himself."*



Nathan Wick had recorded his wishes with the Missouri Organ Donor Registry.

Analysis of registry demographics shows 43% of Missouri adults (ages 18 to 64) are in the Organ Donor Registry.

Procurement Agency Staff commend work of Team

Even though the registry has existed for many years, it has only been truly functional for the last couple. It is because of your diligence and hard work that today we now have a registry that can be useful in helping families make that important decision to donate. It was a long and difficult road which was filled with obstacles but you have risen to the challenge and overcome every adversity put in your path. We now have the ability to check the registry in real time over the web with backups in place to ensure 24 hour access. Thank you again for all of your hard work.

Lori Schutte

Vice President, Program Development
Mid-America Transplant Services

The Registry has definitely enhanced the referral/requesting process. It is so accessible now and gives us the opportunity to help families in a much more professional manner. I had one situation that I can give an example and that was a husband who knew his wife had him witness something, but was not sure and could not find anything at home. When I called the communications center at MTS and had them fax me a hard copy of her registry information, and then shared it with him, he felt confident and more comfortable that he was making the right decision, because it was also something that she had wanted. I was also at the hospital the other day and pulled the web-based registry up for our own use rather than calling our communications center. It saved us time. Thank you so very much for all the effort and thought that has gone behind development of the Missouri Donor Registry.

Marsha Buck

Donor Family Services Coordinator
Mid-America Transplant Services

As not only a member of the advisory committee but as one who utilized both methods of accessing the registry, I cannot thank the development team enough. The web based system has made it possible for the recovering agencies of Missouri to assist families with immediate information when it is needed. This ease of access is nothing short of miraculous when compared to the old system. Thank you so much for eliminating the frustration of the old antiquated system and allowing us to move into the "information age" with stellar aplomb.

Dee Thompson

Mother of Organ Donor and member of
Gov. Organ Donation Advisory Committee



Missouri Organ Donor Registry

Summary highlights Missouri's need and accomplishments.

The Problem

- The need for organ donors is critical. Currently, more than 3,200 Missourians are waiting for a life-saving transplant. The number grows to 81,000 nationally. Approximately 15 people die every day in this nation, while waiting for a donated organ.
- Federal regulations designed to increase donation were implemented in 1998 and require that all families of potential donors be asked about organ and tissue donation. Unfortunately for families who never had a discussion about the deceased person's wishes, the decision on organ and tissue donation can be very uncertain and difficult to make.
- The key to meeting the critical need for donors is to encourage more people to be donors and express their decision. The most valuable expression is a family conversation. However, the Missouri Organ Donor Registry is a vital link for families, especially those who are faced with the question of donation and had no prior knowledge of their loved ones wishes. The Missouri Organ Donor Registry is a confidential, computerized list of potential organ and tissue donors. Registry information is shared with the family who is asked to consent for donation on the behalf of a deceased individual.

Missouri Initiatives and Accomplishments

- Missouri's Organ Donor Registry is legislatively mandated as a function of the Department of Health and Senior Services (DHSS). Missouri was one of the first states to have a computerized donor registry. Though the original system, built in 1997, used modern technology at the time, current needs of the users had surpassed the original technology. The organ and tissue procurement agencies (users of the system) recognized the potential impact of registry information in the lives of Missourians and requested improvements in the old registry so that the information on potential donors could be accessed and utilized more effectively.
- DHSS staff from the Organ Donor Program (ODP) contacted the Office of Information Systems (OIS) to see if a more customer-friendly, electronically sophisticated system could be developed. OIS quickly put together a team to respond to this request. While the task was daunting, the project was completed in record time. Extensive collaboration between OIS and ODP staff maximized efficiency during the development process and ensured that the delivered product met the needs with no significant revisions required. Additionally, collaboration between OIS and ODP staff facilitated a smooth implementation process for the procurement agency personnel transitioning from the old system to the new system. The enhanced system is now accessible 24 hours per day, has a freestanding back-up system, and twenty-four hour/day, seven-days/week technical assistance. Completion of this project represents DHSS's first web database application allowing access to information by authorized users from any Internet connection. In addition to the success of this project, the design and architecture of this application has served as a model for other new software development.
- Department of Health and Senior Services works closely with the organ and tissue procurement agencies to assess the effectiveness and reliability of the Web-based Organ Donor Registry. All structure and process measures indicate that the system is functioning as desired and the procurement agencies remain highly satisfied with the performance of the new system. As an outcome measure, Mid-America Transplant Services (MTS) is performing comprehensive analysis on the impact of registry information on the donation consent process. As described in the full nomination, MTS documented 33 Missouri donors over a 6-month period where the family was not inclined to consent to donation because they had no prior knowledge of the deceased's wishes on donation. Having evidence of registry participation, they consented to donation. Thus, the donations from those 33 donors are a direct result of the Organ Donor Registry and have the potential to help as many as 130 people awaiting life-saving organ transplants and several hundred more through tissue and corneal transplants.

Lori, Congratulations to you and the team on the Quality and Productivity Award. From the perspective of Midwest Transplant Network, the work that was done on the Registry sets the standard for "quality and productivity" and for donor registries nationwide. Please extend our congratulations and thanks to everyone involved in this important project.. Best regards.

Rob Linderer
Executive Director
Midwest Transplant Network

I would like to take this opportunity to sincerely congratulate all of the outstanding members of the Department of Health and Senior Services' Development and Implementation Team for the Web-based Organ Donor Registry, recipients of the Governor's Award for Quality and Productivity. Your efforts to make the Missouri Donor Registry one of the best in the Country have resulted in saving the lives of a number of your fellow Missourians...and improving the lives of hundreds more. As a direct result of the improvements you have effected in The Registry, families of potential organ and tissue donors are now able to be informed about their loved-one's wishes. Without this benefit, families would still be faced with questions about their loved-one's intentions with respect to donation. On behalf of the Missouri Organ and Tissue Donor Advisory Committee, Mid-America Transplant Services, and speaking for families of donors and recipients, congratulations and thanks.

Lonnie M. Boyd
Vice President Regional Services
Mid-America Transplant Services

Having just completed one year at MTS I have only seen 2 small revisions (including my suggestion of adding forward slashes to the DOB box). Being a resident of Illinois and having to call them each time I need a check, I have come to really appreciate the ease of computer-based accessibility of the Missouri Registry; especially the ability to provide immediate information to the caller instead of having to callback at a later time (particularly if our phones get busy). Secondly, it is nice to have 2 back-up methods in place in case of the Internet system "going down."

David Stahlhut
Triage Coordinator
Mid-America Transplant Services